

# 2011 Military Health System Conference

## The Patient as Partner

Putting the Patient on Your Care Team

*The Quadruple Aim: Working Together, Achieving Success*

“e-Patient Dave” deBronkart

January 26, 2011





# Thank you for your service.



# How I came to be here today



- High tech marketing
- Data geek; tech trends; automation
  - 2007: Cancer kicker
  - 2008: E-Patient blogger
  - 2009: Participatory Medicine, Public Speaker
  - 2010: full time

“I want to note especially  
the importance of the resource that is  
most often under-utilized  
in our information systems -  
our patients”

*Charles Safran MD, Beth Israel Deaconess  
and Harvard Medical School  
Testimony to the House Ways & Means  
subcommittee on health, 2004*





**e-patients.net**

because health professionals can't do it alone



Doc Tom said,

"e-Patients are

**E**quipped

**E**ngaged

**E**mpowered

**E**nabled"

e-Patients.net

founder

Tom Ferguson

MD

1944-2006



# e-patients.net

because health professionals can't do it alone



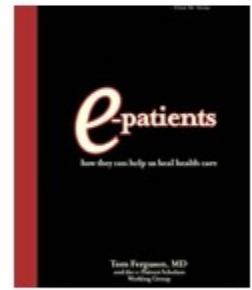
Search this website...

John Sharp,  
Cleveland Clinic:



“If you have not read  
the e-Patient White  
Paper, you do not  
understand the future  
of medicine.”

white paper



e-Patients:  
How They Can Help Us Heal  
Healthcare

- Download the PDF (977 KB)
- Read/Edit the Wiki Version

# Society for Participatory Medicine



Bringing together e-patients and health care professionals.

Home Declaration Blog Journal Join Us Member List About Us

*Participatory Medicine is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners.*

## Welcome

Participatory Medicine is a cooperative model of health care that encourages and expects active involvement by all connected parties (patients, caregivers, healthcare professionals, etc.) as integral to the full continuum of care. The 'participatory' concept may also be applied to fitness, nutrition, mental health, end-of-life care, and all issues broadly related to an individual's health.

The Society was founded to learn about and promote Participatory Medicine through writing, speaking, social networking, and other channels. [Join us!](#)



Our two founding core initiatives are the [e-patients.net](#) blog and the [Journal of Participatory Medicine](#).

 Search

### The Society

- [A Declaration of Participation](#)
- [About Us](#)
- [Journal of Participatory Medicine](#)
- [Join Us](#)

### The Journal

- [About the Journal](#)

### White Paper

- [e-Patients: How TheyCan Help Us Heal Healthcare \(PDF, 977 Kb\)](#)

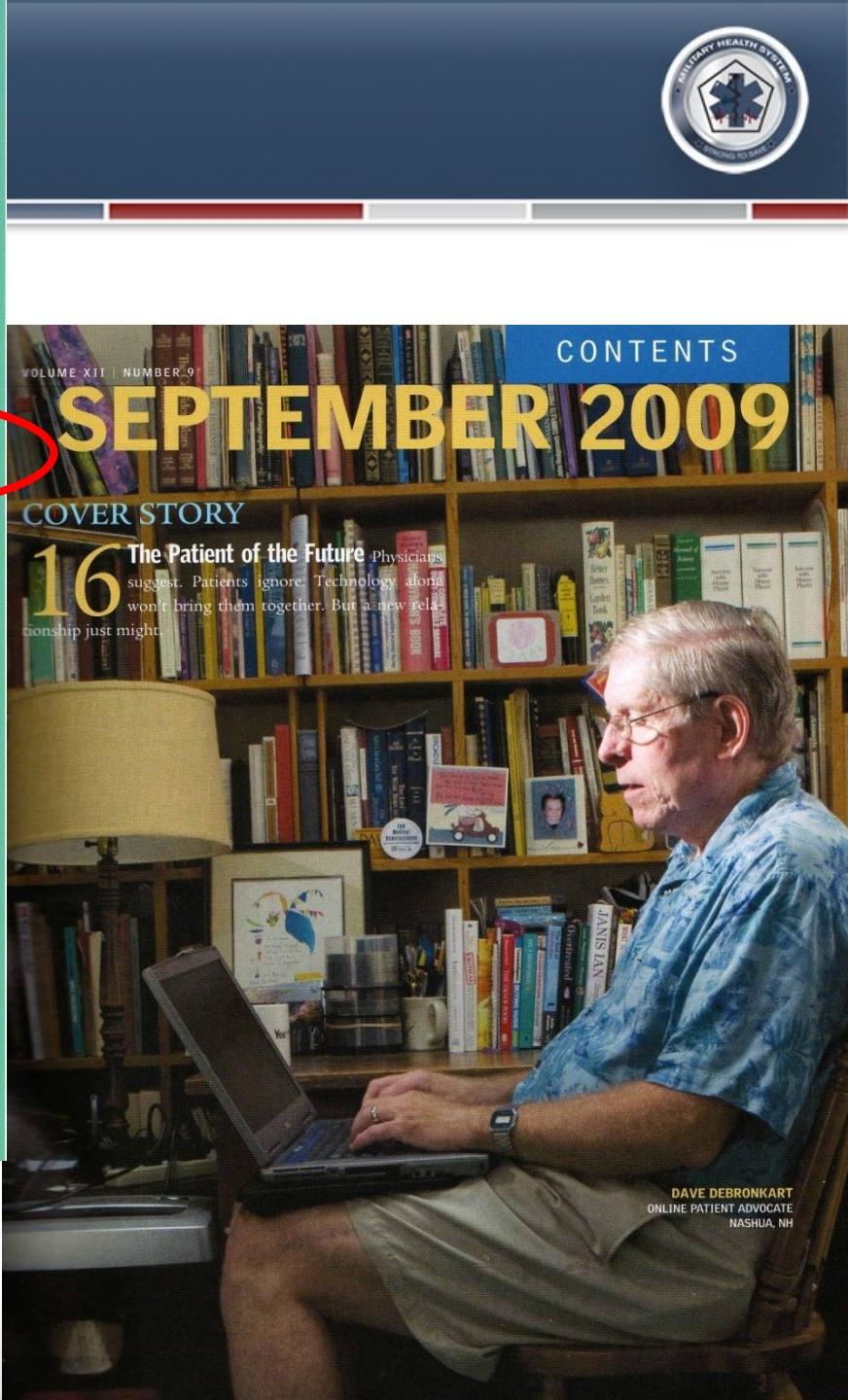
### Founding Organizations



### Forums

- [e-Patient Stories](#)
- [General Discussion](#)
- [Medical Records & Technology](#)

**"Networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners."**



2011 MHS Conference

# 20 PEOPLE WHO MAKE HEALTHCARE BETTER

The very essence of healthcare is to make a difference for good. At its core, this is an industry focused on making life better for people. That simplicity of mission establishes a shared grounding for the millions who work daily to deliver the best healthcare they can. In our annual *HealthLeaders 20*, we offer profiles of some who are doing just that. You can read long form versions of each of these profiles, and listen to audio interviews online by visiting [www.healthleadersmedia.com/20people/](http://www.healthleadersmedia.com/20people/).

## > THE UGLY TRUTH ABOUT COST

**Atul Gawande, MD**

If you worked in healthcare in 2009, someone told you to read the article. Even the president of the United States held up the article as required reading for those who would understand why healthcare reform is so urgent.

Even months later, Atul Gawande, MD, wonders how his article "The Cost Conundrum" in the June 1 *New Yorker* struck a very raw nerve. Part of what gives Gawande's mass-audience writing on healthcare such heft is his blend of a physician's knowledge with a master storyteller's need to find the problem where it lives. Many had dissected the academic data. Medicare costs put out by the Dartmouth Atlas, but Gawande says that only told part of the story.

"The whole reason I wrote it is that I wasn't certain of what to make of the Dartmouth data," Gawande says. "It seemed to me that I had a second problem, which was that we didn't understand what to do about costs."

The reaction to the story was reassuring to Gawande, but not just because so many people in high places referenced it. To Gawande the reaction was so strong was an affirmation of why he writes a story: because he doesn't fully grasp an important issue and hopes his exploration of the answers is shared.

He also takes some pride in those who chose to use his article as a point in the ongoing healthcare reform debate came from both sides of the political aisle. "They might disagree about how you solve it, but if it helps crystallize the problems that we want reform to solve in order to make care better—not just cheaper but generally better—that is what all my work is about."

—JIM MOLPUS

## > TRYING TO DELIVER MIRACLES

**Dean Kamen**

While still in high school, Dean Kamen was making money by designing light and sound systems

for rock bands and museums. Pretty cool. But early on in his career, the renowned inventor determined to focus on "the really important stuff that can make a big difference to people."

Much of Kamen's work is dedicated to healthcare and medical products. Among his inventions: the AutoSyringe wearable infusion pump; the Homechoice PD, a peritoneal dialysis machine; and the iBOT self-balancing wheelchair.

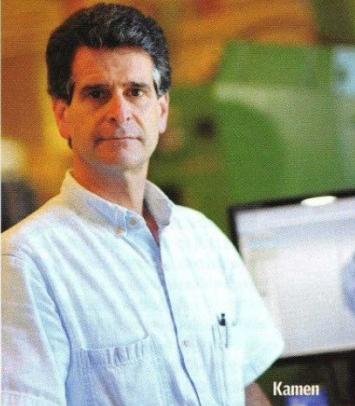
Kamen's latest healthcare breakthrough is a robotic prosthetic being developed for the military. The DEKA Arm virtually reacts to the user's thoughts, an arm and hand that has the sensitivity to distinguish among and handle objects as diverse as a razor blade and a grape, all the while using a range of motion akin to a healthy, human arm.

Kamen lives at a hilltop estate in Bedford, NH. He often pilots his own helicopter from there to his DEKA Research and Development Corp., which employs about 300 in the city of Manchester, NH.

"I get passionate about trying to solve a problem. I've got some really, really smart people here that will jump all over trying to deliver miracles. It's fun, it's exciting, and when it works, it makes us feel pretty good about ourselves and the future."



Gawande



Kamen



deBronkart

spreading the word," says deBronkart. "And sooner or later everybody will be headed to our party."

—GIENNA SHAW

The theme of personal responsibility is also essential to Kamen's vision. "We're going to have to stop assuming we are recipients of magic from 'them'—whoever the 'them' is, whether it's the insurance company or the government or your doctor. There's no 'them' out there. It's going to be a world where people are responsible, they are not recipients; they're customers, they're patients, and they're going to be involved in preventing diseases and hopefully treating them more effectively than passively being the recipient of a process."

—BOB WERTZ

## > PATIENT ENGAGEMENT ADVOCATE

**Dave deBronkart**

Dave deBronkart is the quintessential engaged patient consumer the likes of whom—depending on your viewpoint—is either an anomaly or an inevitability.

In 2007, deBronkart was diagnosed with stage four kidney cancer. His Boston-based physician,

Daniel Sands, MD, introduced him to the cancer-support site Acor.org, which has an online chat room for kidney cancer patients.

Soon after, deBronkart was invited to join a meeting of ACOR's e-patient scholars working group—which Sands was a member. After that, deBronkart became an active blogger on e-patients.net and took on the online handle that many know him by: ePatientDave.

"My life just pivoted like on a railroad turntable at that moment."

Now deBronkart often works late into the night, spreading his patient empowerment message in chat rooms, on blogs, via Twitter, and in other forums. More recently, deBronkart and Sands became co-chairs of the board of directors for the Society for Participatory Medicine, another e-patients.net offshoot. Through all these venues, deBronkart's main message reverberates: Patients have the right to know and pursue their options. He believes that "great doctors saved my life," but patients can and should contribute to their own care.

As for whether or not engaged patients are an anomaly or an inevitability? "All I can say is we're

## > EARLY ADVOCATE FOR PATIENT E-MAIL, ENGAGEMENT

**Daniel Sands, MD**

A decidedly non-Asian physician, Daniel Sands, MD, says, "If I had my druthers, I would take care of only patients who are engaged." A physician at the 621-bed Beth Israel Deaconess Medical Center in Boston, Sands says, "I've always been interested in what we now call participatory medicine. It's the way I like to practice."

From writing guidelines for communicating with patients via e-mail to helping to develop clinical decision support systems and patient portals, Sands is also a huge advocate of using technology to improve the patient experience. And he can only be described as an early adopter.

# Me? An indicator of the future??

- Who's getting online:
  - 1989: Me (CompuServe sysop)
  - 2009: 83% of US adults (Pew)
- Who's romancing online:
  - 1999: I met my wife (Match.com)
  - 2009: One in eight weddings in the U.S. met online



I'm like JFK:  
**“They sank my boat”**

# The Engaged Patient, 2006



## Ophthalmic migraine?

- Shape of the disturbance is exactly as shown at right (from <http://www.richmondev.com/simulation.asp#migraine>).
- But the interior is dazzling, not the pattern shown here.
- Behavior is as described at that site and others (see log below)
- The shape may point left or right.



#	Date	start	gone by	Notes
1	30-Oct		(approx)	
2	4-Nov	8:58	9:22	Wife's 60th birthday
3	21-Nov	12:35	12:50+	Long gone by 1:30. Different shape this time - almost a mirror of the other, right of center, below center. Note - Thanksgiving was 11/23
4	25-Nov	19:40		The usual Nike-like chevron. Note: with both eyes closed it's like yellow & black stripes.
5	6-Dec	12:05	before 12:50	Start: non-specific sense of dazzle;

## Shoulder

- Range of motion complaint: "right shoulder is having range of motion trouble. No discomfort, but it just doesn't seem to work right: I find myself lifting my shoulder instead of the arm."
- Made a Jan 2 appointment w/ Dr Zilberfarb

# The Incidental Finding

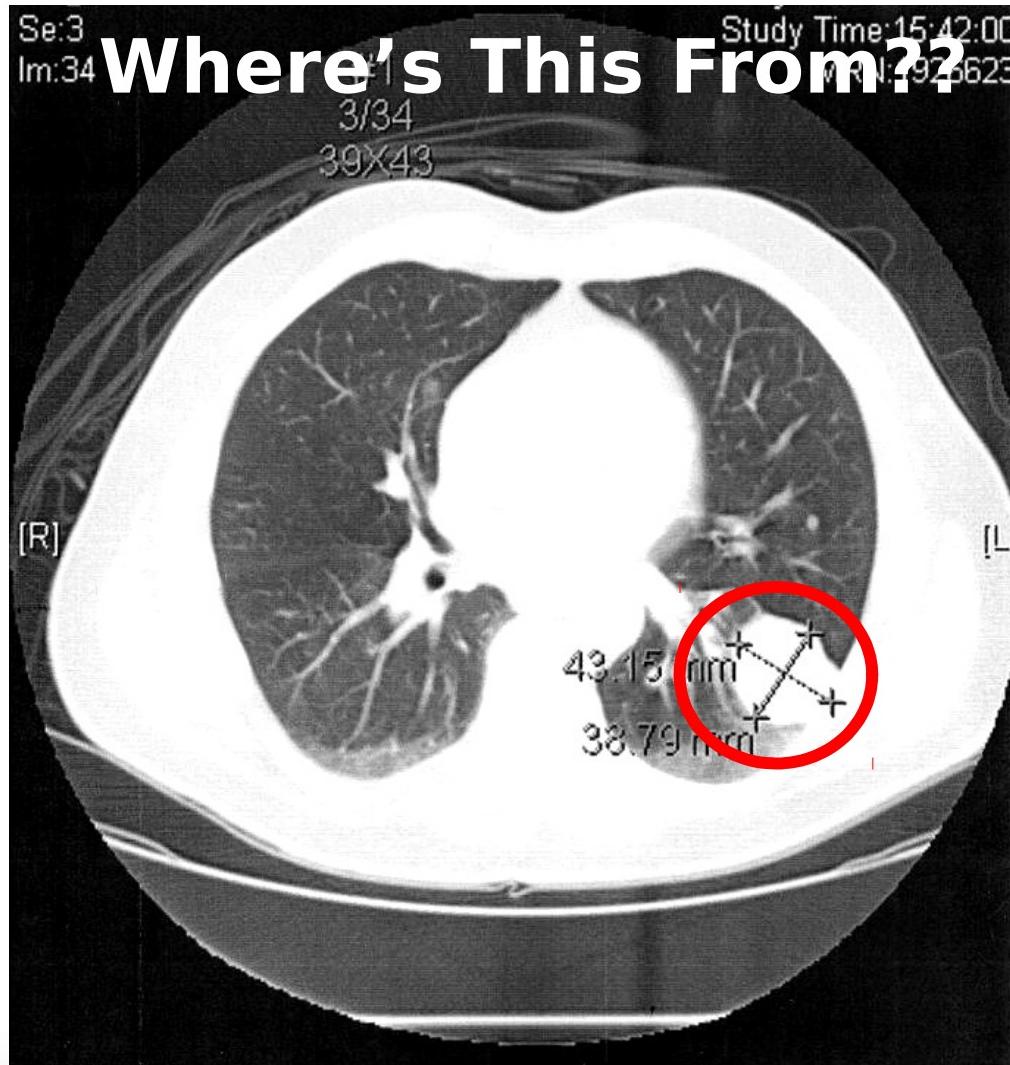


*Routine shoulder x-ray  
Jan. 2, 2007*

*“Your  
shoulder  
will be fine  
...  
but there’s  
something  
in your  
lung”*

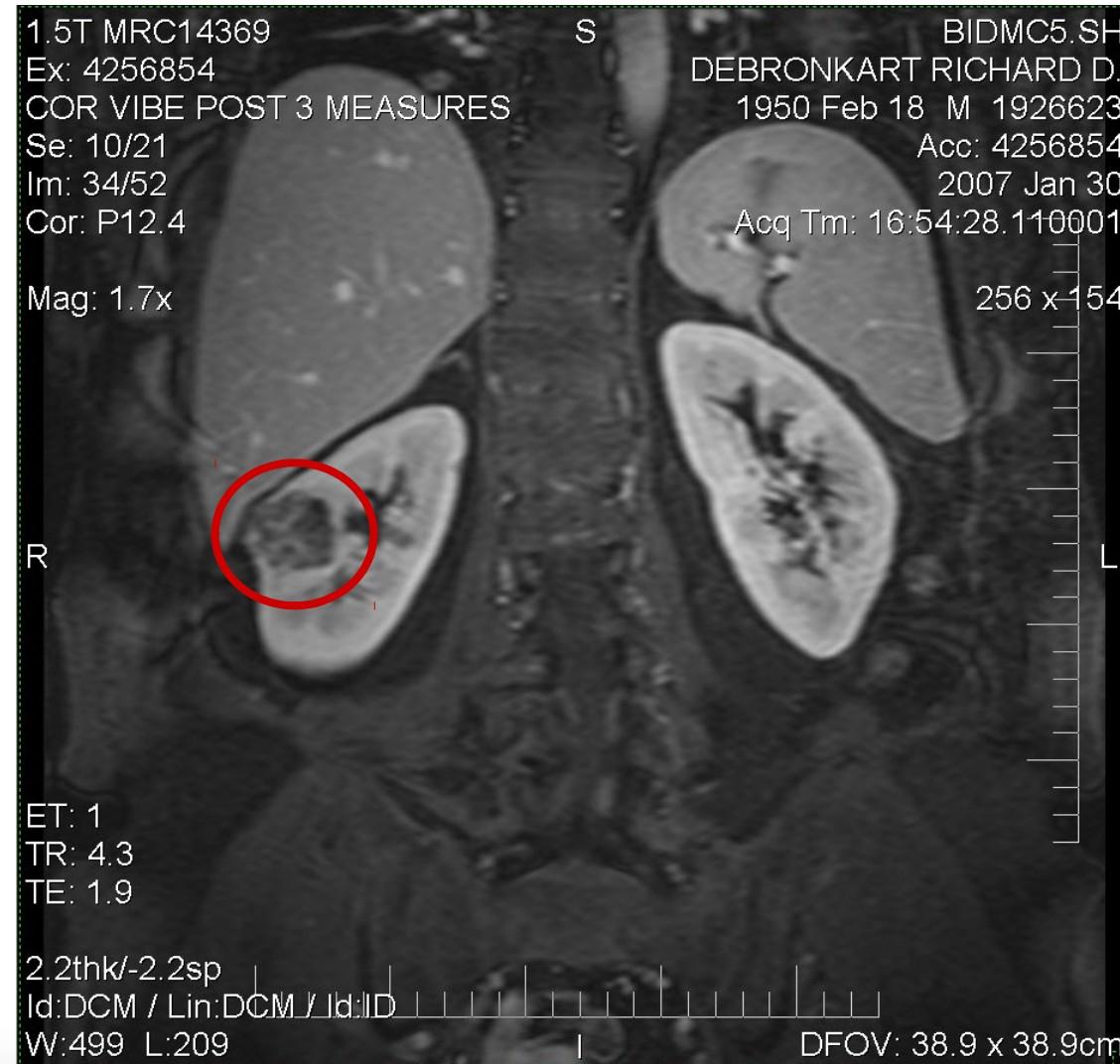


# Multiple tumors in both lungs





# Primary Tumor: Kidney



# E-Patient Activity 1



**WebMD**  
Better information. Better health.

SEARCH

HOME HEALTH A-Z DRUGS & TREATMENTS WOMEN MEN CHILDREN'S HEALTH

# Researching my condition

**Renal Cell Cancer Treatment (PDQ®)**

- Purpose of This PDQ Summary
- General Information
- Cellular Classification
- Stage Information
- Treatment Option Overview
- Stage I Renal Cell Cancer
- Stage II Renal Cell Cancer
- Stage III Renal Cell Cancer
- **Stage IV and Recurrent Renal Cell Cancer**
- Get More Information From NCI
- Changes to This Summary (03/10/2008)
- More Information

**Related To**

All Cancer Topics  
Bladder Cancer  
Brain Cancer  
Cervical Cancer  
Healthy Living Calendar

**Cancer Health Center**

Renal Cell Cancer Treatment (PDQ®) - Stage IV and Recurrent Renal Cell Cancer

FONT SIZE A A A

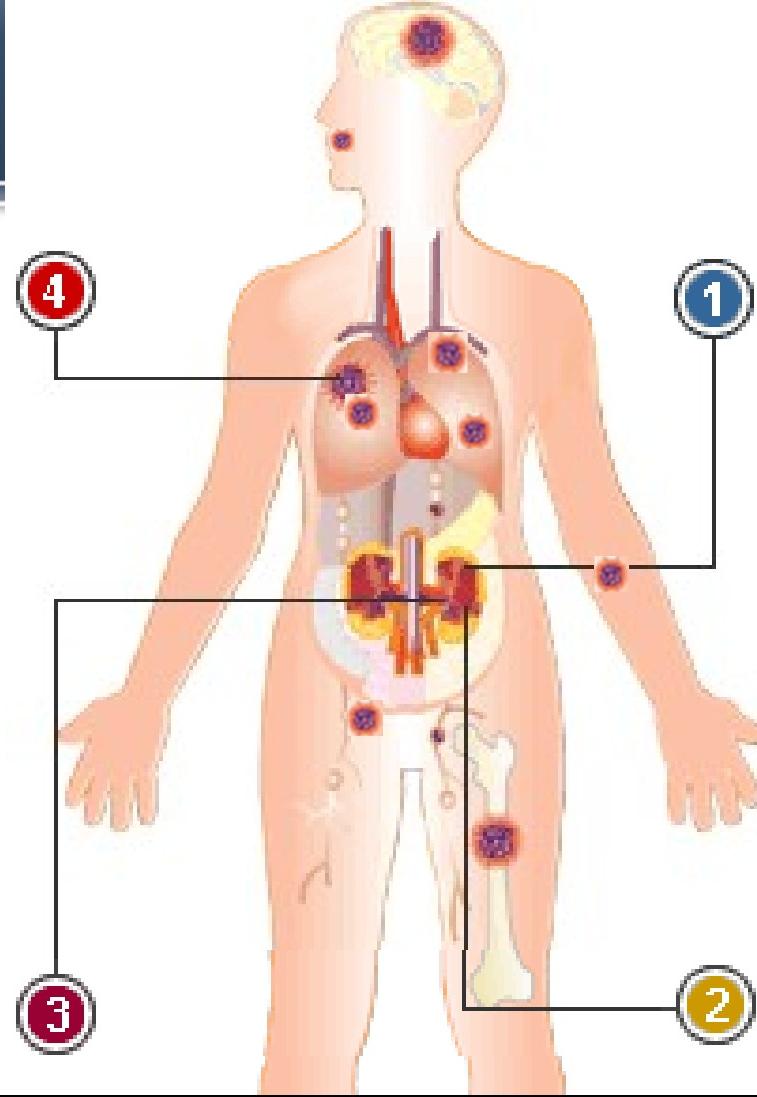
*Stage IV renal cell cancer is defined by the following stage groupings:*

- ❖ T4, N0, M0
- ❖ T4, N1, M0
- ❖ Any T, N2, M0
- ❖ Any T, any N, M1

The prognosis for any treated renal cell cancer patient with progressing, recurring, or relapsing disease is poor regardless of cell type or stage. Almost all patients with stage IV renal cell cancer are incurable. The question and selection of further treatment depends on many factors, including prior treatment and site of recurrence as well as individual patient considerations. Carefully selected patients may benefit from surgical resection of localized metastatic disease, particularly if they have had a prolonged, disease-free interval since their primary therapy. Because of early reports of success, progestational agents have been administered to patients with metastatic renal cell cancer, but the response rates have been disappointingly low; therefore, no rationale

# Classic Stage IV, Grade 4 Renal Cell Carcinoma

Illustration on  
the drug company's  
web site



## Median Survival:



# Finally, a Symptom (6 weeks post-x-ray)

617667ORTHO1  
Ex: 4300321  
Femur  
Se: 4558/1  
Im: 2/4

Mag: 0.4x  
Lat: R

Beth Israel Deaconess  
DEBRONKART RICHARD D.  
1950 Feb 18 M 1926623  
Acc: 4300321  
2007 Mar 19  
Acq Tm: 12:23:36:000



Lin:DCM / Lin:DCM / Id:ID  
NORMAL W:16383 L:8192

# Facing the Reaper



# My mother



# My daughter





After the shock  
you're left with the  
question:  
What are my options?  
What can I do?





Get engaged.

Get it in gear.

Do everything you can.



# E-Patient Activity 2:

## “My doctor prescribed ACOR”

(Community of my patient peers)

The free online lifeline for everyone affected by cancer & related disorders

acor.org

Association of Cancer Online Resources

Home Dictionary Help Site Map

Find a mailing list Search

**WELCOME**  
Association of Cancer Online Resources

ACOR is a unique collection of online communities designed to provide timely and accurate information in a supportive environment.

ACOR offers access to mailing lists that provide support, information, and community to everyone affected by cancer and related disorders.

**MAILING LISTS**

- ONLINE COMMUNITIES

**SUPPORT & RESOURCES**

- COPING WITH CANCER

**TYPES OF CANCER**

- ALPHABETICAL LIST

**TREATMENT OPTIONS**

- CURRENT TREATMENTS

**CLINICAL TRIALS**

- EXPERIMENTAL TREATMENTS

**PUBLICATIONS**

- CANCER-RELATED BOOKS

**PARTNERSHIPS**

- ALLIANCES & FRIENDS

**HELP ACOR**

- DONATIONS & VOLUNTEERS

**News**

Fat tissue-derived hormone leptin increases e-cadherin expression, obesity-breast cancer link noted

Being obese increases the risk of breast cancer in post-menopausal women, shortens the time between return of the disease and lowers overall ...  
Apr 29, 2007  
[Full Story]

**What's New**

Please Note: Mar 26, 2007  
Update: We have started



# E-Patient Activity 3:

## Reading (and sharing) my hospital data online

Beth Israel Deaconess Medical Center  
**PatientSite**  
Your Health. Online.

Welcome to the Personal Health Website of Richard Davies deBronkart • Sign Out

Records of Richard Davies deBronkart [Security Audit] Help

BIDMC MyEntries

Problems Reports Meds Allergies Visits X-rays Labs Micro

Date	Exam	Status
03/30/09 4:13 PM	E141R FOREARM (AP & LAT) RIGHT	APPROVED
03/30/09 4:13 PM	E221L FEMUR (AP & LAT) LEFT	APPROVED
03/30/09 4:13 PM	E212R HIP UNILAT MIN 2 VIEWS RIGHT	APPROVED
03/10/09 3:24 PM	Q992 CT CHEST W/O CONTRAST W/ONC TABLES	APPROVED
03/10/09 3:24 PM	Q995 CT ABDOMEN W/O CONTRAST W/ONC TABLE	APPROVED
03/10/09 3:24 PM	Q998 CT PELVIS W/O CONTRAST W/ONC TABLES	APPROVED
12/09/08 4:10 PM	Q992 CT CHEST W/O CONTRAST W/ONC TABLES	APPROVED
12/09/08 4:10 PM	Q995 CT ABDOMEN W/O CONTRAST W/ONC TABLE	APPROVED
12/09/08 4:10 PM	Q998 CT PELVIS W/O CONTRAST W/ONC TABLES	APPROVED
09/04/08 3:32 PM	Q411 CT CHEST W/O CONTRAST	APPROVED



# E-Patient Activity 4:

## My own social support network

Dave deBronkart

WELCOME • my story • journal • guestbook • photos • links • tributes • author sign in • help

**MY STORY**

1/30/07:

On January 2 a routine shoulder x-ray showed a mass in a nearby part of my lung. Four weeks later, it appears to be kidney cancer that's spread to both lungs. This site will chronicle the learning and emotional processes we're going through as we learn and do everything we can to maximize my chances. Top of the list: a strong mental attitude and a clear mind!

[★ Read Story](#)

**JOURNAL**

WEDNESDAY, APRIL 25, 2007 06:16 PM, EDT

I want to receive journal update notifications

**HELP SOMEONE ELSE WHEN THEY NEED IT MOST**

[Tell a Friend](#) about CaringBridge.

**TRIBUTE DONATIONS TO CARINGBRIDGE**

[Read the caring tributes](#) in honor of Dave.

[Make a donation](#) to CaringBridge to help provide this service to others who may need similar support.

**4866 VISITS FROM FAMILY AND FRIENDS WHO CARE**

**HOSPITAL INFORMATION**

Beth Israel Deaconess Medical Center, Boston  
United States



# E-Patient Activity 5:

## Tracking my Data

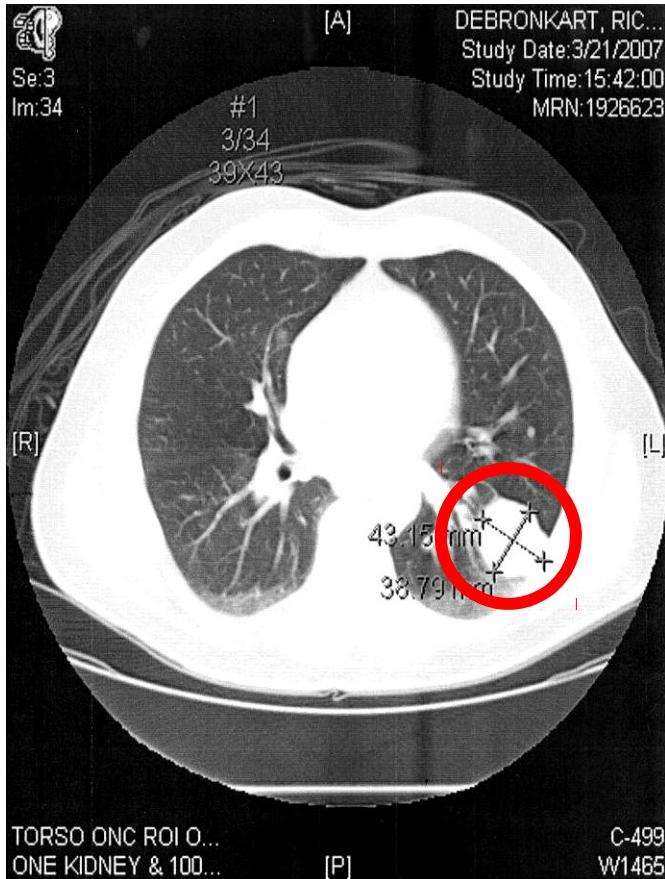
A	B	C	D	E	F	G
<b>Chest x-rays and scans</b>		5-Jan	30-Jan	21-Mar	APRIL	14-May
<b>Target Lesions</b>	Slice	CT	MRI	CT	R	CT
Target #1 (left lower)	34-36, mid right			43x39	O	37x35
Target #2 (right upper lobe)	23-24, lower left	30[1]		41x33	U	42x32
Target #3 (apex of right lung)	13, near trachea on left			24x22	N	14x11
Target #4 (Left upper anterior)	40, front of left lung		43x	20x13	D	24x14
<b>SCORE</b>				38.18	1	31.29
			Reduction since March 07			
						Re

do'



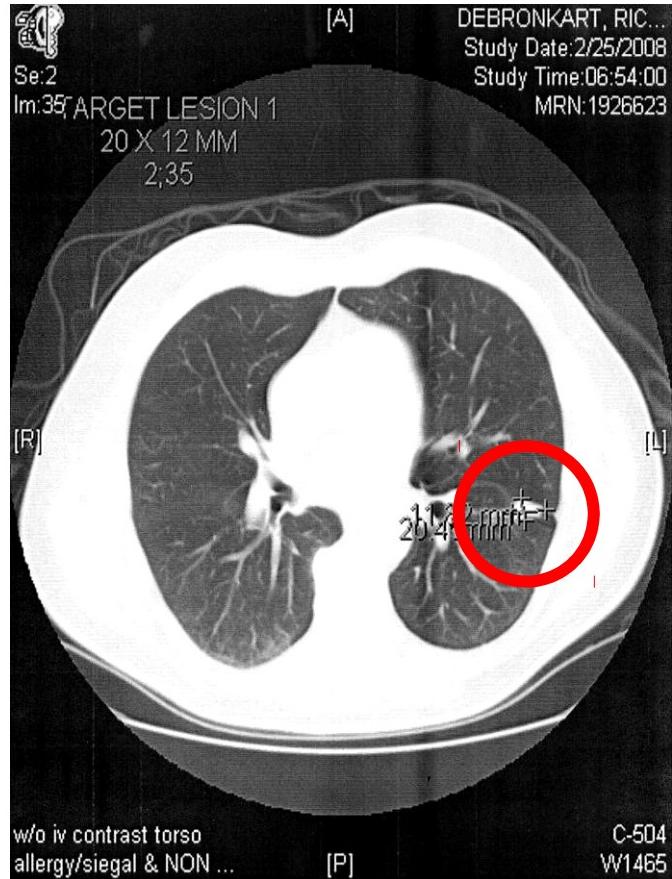
# Surgery and Interleukin worked.

## Target Lesion 1 - Left Upper Lobe



Baseline: 39x43

2011 MHS Conference mm

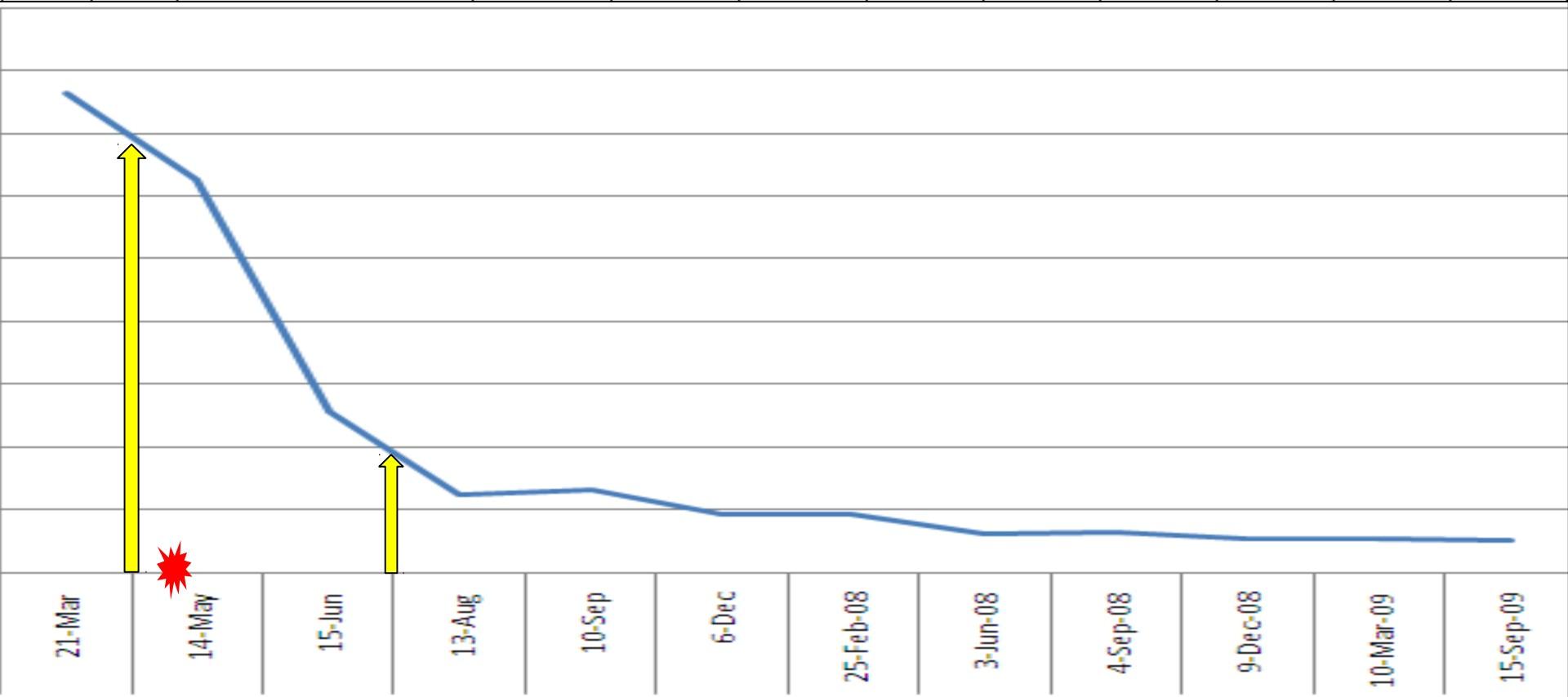


50 weeks: 20x12  
mm



# Victory!

E	F	G	H	I	J	K	L	M	N	O	P	Q	R
21-Mar	APRIL	14-May	15-Jun	JULY	13-Aug	10-Sep	6-Dec	25-Feb-08	3-Jun-08	4-Sep-08	9-Dec-08	10-Mar-09	15-Sep-09
CT	R	CT	CT	R	CT	CT	CT	CT	CT	CT	CT	CT	CT
43x39	O	37x35	29x23	O	22x13	21x13	18x11	20x12	17x9	17x9	17x8	17x8	17x7
41x33	U	42x32	20x18	U	15x15	17x15	14x12	13x13	13x10	13x11	11x10	11x10	11x10
24x22	N	14x11	14x11	N	8x8	stable	8x7	6x8	6x4	5x5	5x5	5x5	6x5
20x13	D	24x14	12x9	D	10x5	stable	7x6	5x2	0x0	0x0	0x0	0x0	0x0
<b>38.18</b>	<b>1</b>	<b>31.29</b>	<b>12.89</b>	2	<b>6.25</b>	<b>6.6</b>	<b>4.64</b>	<b>4.67</b>	<b>3.07</b>	<b>3.21</b>	<b>2.71</b>	<b>2.71</b>	<b>2.59</b>
n since March 07		18%	66%		84%	83%	88%	88%	92%	92%	93%	93%	93%
Reduction since June:					52%	49%	64%	64%	76%	75%	79%	79%	80%





# E-Patient Activity 6:

## Start a blog (pay it forward)

### The New Life of Patient Dave

In 2007, supported by an extraordinary team of family, friends, and medical staff, I stomped the snot out of a nasty cancer that was on its way to killing me. I've since learned that the way I did it has a lot in common with the advice of the "e-patients" movement, so I've changed my blogger name from Patient Dave to e-Patient Dave.

Thursday, November 29, 2007

### Thank you, Beth Israel Deaconess!

People have different views of what causes what in life, and that's fine with me. On this blog you'll hear lots of thoughts about that.

Here's one of my strongest opinions: I wouldn't be here writing this if it weren't for some extraordinarily good people at [Beth Israel Deaconess Medical Center](#) (BIDMC) in Boston.

It's not fair to include some names and not others, but since they have 6,000 employees, I've got to stop somewhere. Here are my heroes:

- **Dr. David McDermott**, of the famous Atkins & McDermott team - among the best in the world for RCC (renal cell carcinoma). You may be a Yankees fan, but I love ya anyway, Dr. McDreamy.



# Thank those who helped

## The New Life of Patient Dave

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Sunday, December 9, 2007

### Thank you, Harvard Pilgrim!

[listen now](#)

[The rant below](#) is about statistics, not insurance companies. But I want to take a moment to thank my health insurance company, Harvard Pilgrim Health Care. My cancer adventure (and house-selling adventure) this year had enough challenges of their own, but the year could have been sheer hell if my insurance company had been a jerk. Harvard Pilgrim was the polar opposite of that.

This year I've run up almost a half million in costs, including dozens of doses of Interleukin-2 at \$7,000 a dose. As I chronicled [in my journal](#), the Interleukin (and skillful hospital staff) saved my life, and I don't think I paid a penny for it, and only paid about a grand for everything else.

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[twitter.com/ePatientDave](http://twitter.com/ePatientDave)

100

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HOSPITALS**



# e-patients.net

because health professionals can't do it alone



Search this website...

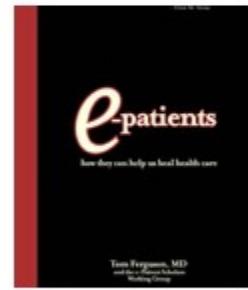
# Get educated / get engaged

it spreads. It starts with a  
our EMR situation today,  
ity, and errors that leak

3 Examples [3 Comments »](#)

EHRs/PHRs

white paper



e-Patients:

**How They Can Help Us Heal  
Healthcare**

- Download the PDF (977 KB)
- Read/Edit the Wiki Version

# **“e-Patient?”**

## **I know one when I see one.**



## **The New Life of e-Patient Dave**

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Monday, January 28, 2008

## **e-Patient? Yes, e-Patient.**

In the past few days, with my discovery on 1/23 of the e-Patient Scholars Working Group, my entire outlook on life has changed - so much so that I'm changing the title of this blog from "Patient Dave" to "e-Patient Dave."

That's because I've found my purpose for this blog. And that in turn is because my experience over the past year is a ridiculously close match for the principles and practices recommended by the group. So I think I've found the answer to a question I've asked in recent months: "What am I going to do, what am I going to create in the world, out of my experiences of the past year?"



# Question:

How can it be  
that the most *useful*  
and *relevant* and  
*up to the minute* information  
can exist outside of  
traditional channels?



# Information explosion

## Dr. Lindberg 400 years

“If I read two journal articles every night,  
at the end of a year I’d be 400 years behind.”

It’s not humanly possible to keep up.



# The lethal lag time:

## 2-5 years

The time it takes after successful research is completed before publication is completed and the article's been read.

During this time,  
people who might have benefitted can die.

Patients have all the time in the world  
to look for such things.



Tom Ferguson, MD  
and the e-Patient Scholars  
Working Group



# Death by Googling:

# Not.

*(Dr. Gunther Eysenbach, Europe) .*

*Compare with*  
**“To Err is Human”**



Tom Ferguson, MD  
and the e-Patient Scholars  
Working Group



**"Arguably it's  
more dangerous  
not to google  
your condition."**



**e-patients**  
how they can help us heal health care

Tom Ferguson, MD  
and the e-Patient Scholars  
Working Group

**"These conclusions  
are no more anti-doctor  
or anti-medicine  
than Copernicus and  
Galileo  
were anti-astronomer."  
Patients can simply  
contribute more today than  
in the past.**



# Participatory medicine

brings  
a shift  
in shared  
responsibility

Blog post, Dec. 2008

**"Physicians are coaches. Patients are players."**

December 31, 2008 · Filed Under [positive patterns](#), [pt/doc co-care](#), [treas & principles](#) · 4 Comments

I don't know who Stanley Feld is, but he just became my friend, with a terrific post on [doctor as coach, patient as player](#). It starts:

**“** *The role of patients with chronic diseases and their physicians must be clear to both patients and physicians. Physicians are coaches. Patients are players.*

This resonates with what's become my favorite item from Chapter 2 of our white paper, *e-Patients: How they can help us heal health care*: Preliminary Conclusion #6, which is "The best way to improve healthcare is to make it more collaborative."

It resonates particularly well with me because my own e-patient community, the kidney cancer group on ACOR.org, taught me that increasingly cancer has become not an immediate threat to life but a chronic condition. Then, when I read *Anticancer: A new way of life*, an astounding idea came to my attention: cancer without disease.

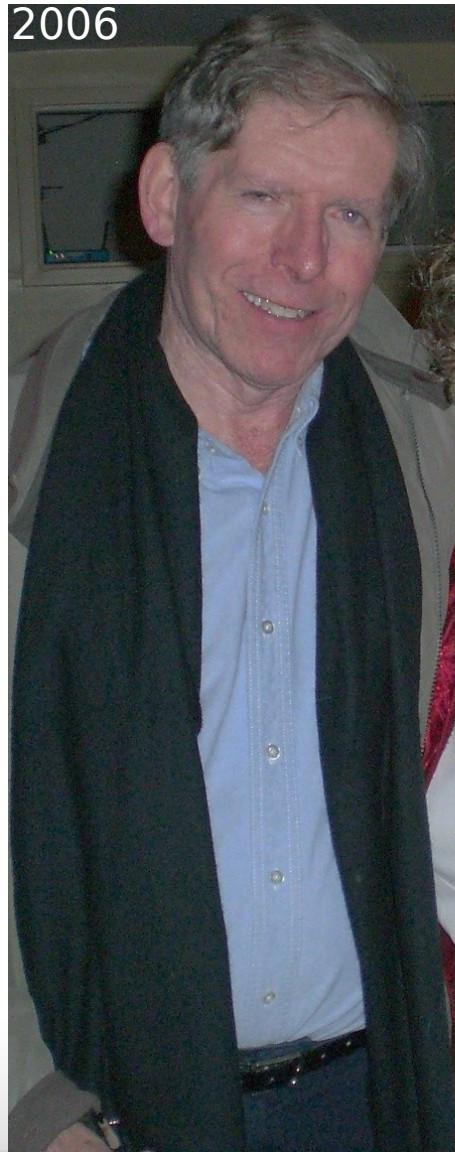
Cancer without disease!

Astounding, and I've never heard it mentioned elsewhere; but here I am, a living example. I still have metastases in me, but I don't have a trace of illness.



# 2.8 e-Patient Years in Pictures!

2006



“I want to note especially  
the importance of the resource that is  
most often under-utilized  
in our information systems -  
our patients”

*Charles Safran MD, Beth Israel Deaconess  
and Harvard Medical School  
Testimony to the House Ways & Means  
subcommittee on health, 2004*





# Much is at stake.



# Patients can help.



Equip them.  
Enable them.  
Show them how.



Make them e-  
Patients.  
Put them on your  
team.

# 2011 Military Health System Conference

## The e-Patient as Partner

Putting the Patient on Your Care Team

*The Quadruple Aim: Working Together, Achieving Success*

“e-Patient Dave” deBronkart

January 26, 2011

